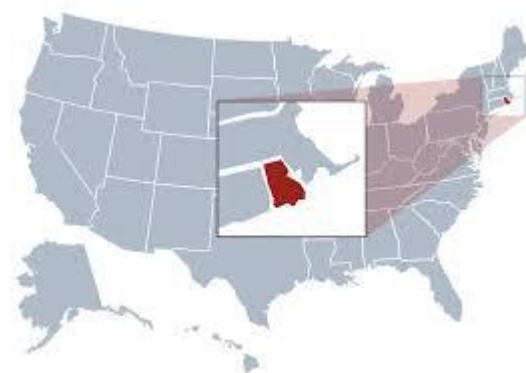


Title V Data Integration State Example: Rhode Island

Background: State System

Rhode Island has a unique and long history of sharing public health data with a range of stakeholders through different systems. First, the [RI DataHUB](#), Rhode Island's Statewide Longitudinal Data System (SLDS), includes public health data, along with data on education, workforce, civic engagement, and juvenile justice. It is managed and maintained by [DataSpark](#), a data integration and analytics group that is part of the University of Rhode Island. Second, the Rhode Island Department of Health manages [KIDSNET](#), a universal database of young children that begins capturing data at birth. This system assigns a unique identifier to children when they are born or when they receive their first immunization or other public health service in the state. Based on a national effort to implement immunization registries, the state used funding from the Robert Wood Johnson Foundation to create a single database for public health information, including immunizations, which provides child-level and aggregate data to medical and other service providers. KIDSNET is linked to the Early Childhood Education Data System (ECEDS) at the RI Department of Education, by linking the KIDSNET ID number to the ECEDS ID. The RI DataHUB, ECEDS, and KIDSNET serve different purposes and audiences, but all provide data to support effective services for children and families.



Integration & Use of Public Health Data

One of the primary ways that the RI DataHUB shares data is through “Data Stories” on its website. The stories guide users through select data related to a key question or policy interest. Many include interactive visualizations and narratives with interpretations of the data. Several of these “data stories” show public health data integrated with other types of data. These stories are publicly available and intended for use by a variety of stakeholders.

The goal of KIDSNET is to coordinate preventative health care for children, but researchers can also request data from the system. KIDSNET is primarily used as a case management system as users can log into the site and view reports on children that they serve. This allows providers to identify gaps in services and make necessary referrals. KIDSNET also provides data to maternal and child health programs, Head Start agencies, child care centers, public school nurses, home visitors, certified lead centers, audiologists, and Managed Care Organizations. The system includes data from the programs/services listed in Figure 1.

Universal	Targeted
Newborn developmental risk	WIC
Newborn bloodspot screening	Early Intervention (IDEA Part C)
Newborn hearing assessment	First Connections (Home Visiting)
Immunization	birth defects
Childhood lead poisoning	Cedar Family Centers (Medicaid intensive care management and coordination)
Vital records (including demographic information)	Healthy Weight
Child outreach screening (RIDE)	Asthma
	Early Childhood Developmental Screening
	Foster Care*
	Head Start**

* = no web access

** = in development

Figure 1: Data in KIDSNET

Data Sharing

While both the RI DataHUB and KIDSNET share data, this section will focus on the data sharing experience of KIDSNET, as it has a stronger focus on public health data.

In its initial phases, KIDSNET did not have data sharing agreements, as all programs in the system were in the same department. As the system has grown, the Department of Health has worked with lawyers to develop data sharing agreements with external programs. Rhode Island benefits from having a broad data sharing policy, which is less restrictive than HIPAA. KIDSNET must comply with HIPAA, but it utilizes the Privacy Rule exception on data sharing which "... permits covered entities to disclose protected health information, without authorization, to public health authorities who are legally authorized to receive such reports for the purpose of preventing or controlling disease, injury, or disability. This would include, for example, the reporting of a disease or injury; reporting vital events, such as births or deaths; and conducting public health surveillance, investigations, or interventions"¹

Data sharing has not been a major barrier to the work in Rhode Island, but can be time-consuming. Some programs have policies that are more restrictive than HIPAA and they must comply with those before sending data to KIDSNET. In addition, some programs, such as WIC, are required to get signed parental consent to share data. To ensure compliance, any dataset requiring parental consent has a field to identify whether consent has been obtained; data will not be pulled unless this field indicates that consent has been given.

Programs are informed of any data request involving their respective data. Programs receive notification but do not approve de-identified data requests. For identifiable data requests, program managers are engaged throughout the data request process and must give permission before any data are released.

¹ HIPAA Disclosures for Public Health Activities, <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/disclosures-public-health-activities/index.html>

Reports & Dissemination

The RI DataHUB provides specific reports on questions of interest for the public, policymakers, school district staff, and others. For example, one of the “data stories” on the site is titled “The Educational Costs of Unhealthy Housing”. It highlights elevated blood lead levels as an indicator for unhealthy housing and connects these data to educational outcomes such as school attendance, grade retention, and proficiency on standardized tests. The study also associates elevated blood levels with higher education costs due to the increased need for Individualized Education Plans (IEPs). This combination of data, and the interpretations provided, informs both school districts and policymakers working to provide efficient and effective education for children. Figure 2 below shows one of the “slides” in the presentation of this data story – an interactive visualization of school attendance of children by highest screened blood lead level.

School Attendance of Children by highest screened blood lead level

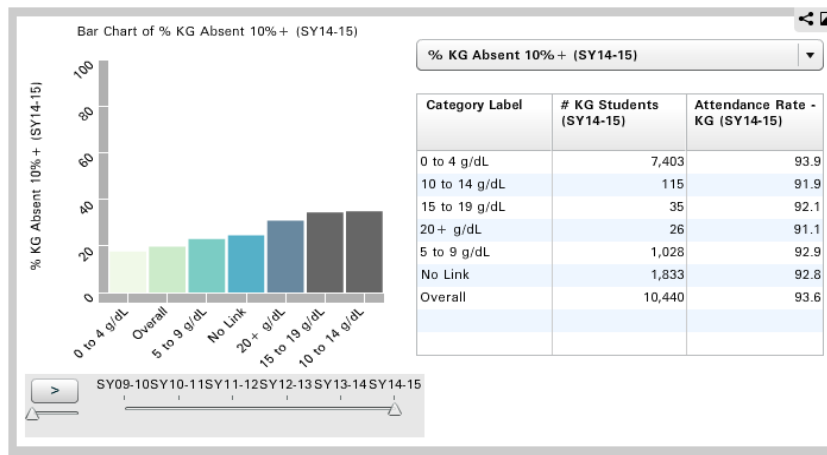


Figure 2: RI DataHub Data Story "The Educational Costs of Unhealthy Housing" Interactive Chart on School Attendance and Lead Levels

The child level reports accessed through KIDSNET include demographic information and can be customized based on pre-designed queries (e.g. newborn summary, early intervention, WIC, home visits). Figure 3 below shows a sample report from the KIDSNET system that a service provider would see on an individual child.

Child Information -06/14/2009	
Demographics	Name: KAREN SMITH KIDSNET ID: 450433
Newborn Summary	Date Of Birth: 11/01/2004 Age: 4y 9m Gender: FEMALE
Child Summary	KIDSNET Status: ACTIVE PCP: DOH TEST PRACTICE
Personal School Form	Parent/Guardian: JANET SMITH Date of birth: 02/11/1980
Newborn Hearing Screening Results	
Lead Poisoning	Date Tested: 12/04/2004 Screen Type: OAE RIGHT EAR Result: PASS
Early Intervention	Date Tested: 12/04/2004 Screen Type: OAE LEFT EAR Result: PASS
Immunization	Screening Result: Pass
WIC	Audiological Recommendation: DISCHARGE FROM RIHAP, NO FURTHER ACTION
Hearing Assessment	Risk Factors:
Detailed Audiological Diagnostic Information	
Newborn	Date Tested: 06/25/2009 Audiologist: KIM AUDIOLOGIST
Developmental Risk Assessment	Diagnosis Left: CONDUCTIVE-PERMANENT Diagnosis Right: NORMAL
Home Visit	Degree Left: MILD Degree Right: N/A
Newborn Bloodspot	Tests performed: Tympanometry, DPOAE, Bone Conduction
Vision	ICD9: Conductive hearing loss unilateral (389.05)
User Management	Secondary ICD9:
	Risk Factors:
	Comments: retest in 6 months

Figure 3: KIDSNET Hearing Screening Report

KIDSNET also produces a publicly available [data book](#) that includes county-level information on child and family health. While this is the only public report available, those without direct access can, as mentioned above, submit data requests through the site for information not contained in the Data Book. Similarly, the RI DataHUB also accepts requests by researchers, state agencies and local community organizations for specific data inquiries and requests. With the exception of researchers, these data are released at the aggregate level. With the appropriate legal arrangements in place, researchers can receive individual de-identified datasets for study.

Value Added

With the implementation of the RI DataHUB, the state has increased the use of and interest in data among Rhode Island's citizens and policymakers. The state has broken down silos, allowing new questions to be answered and leading to further inquiry into how to best support children and families.

KIDSNET has had several direct impacts on programs and policies. KIDSNET is collaborating with the Rhode Island Department of Education (RIDE) to identify children ages 3 to 5 who are eligible for Child Outreach Screening, which is a requirement of IDEA. School districts previously used their own systems to identify children, but Rhode Island used Race to the Top – Early Learning Challenge funding to build a data system for Child Outreach Screening into KIDSNET. The implementation of this change helped them identify their “denominators”, improve outreach efforts, and identify children being screened. They have also added an indicator to help school districts prioritize focus and outreach on children who are high-risk. KIDSNET has also begun collecting developmental screening data on children birth through three from primary care providers. Screening tools captured include Ages & Stages Questionnaire (ASQ), the Survey of Well-Being of Young Children (SWYC), and the Modified Checklist for Autism in Toddlers (M-CHAT). Through KIDSNET these data are linked to birth risk factors and program participation providing an opportunity to learn more about these children.

Another benefit from the widespread use of KIDSNET is the improved collaboration and coordination of services to children and families. For example, WIC programs have implemented a policy to ensure that staff run reports from KIDSNET to identify children who need immunizations and lead screenings. This has led to more referrals from WIC to other services.

Key Takeaways

Rhode Island's success in sharing and using public health data is due to a long-standing commitment to using data for continuous improvement. The state has benefited from broad data sharing policies and strong buy-in within the Department of Health. This strong culture of collaboration was leveraged to show other Departments the value of sharing data before seeking their involvement in the RI DataHUB and KIDSNET. Strong coordination across sectors and innovative ideas have kept Rhode Island's data systems sustainable as they can receive additional funding to support their data work.